### **CURRICULUM VITAE**

## Sylvia Mann Au, M.S., C.G.C.

## **Personal**:

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Languages: English and Chinese (Cantonese)

**Board Certification:** 

1993 American Board of Genetic Counseling

**Education:** 

1986-1988 Sarah Lawrence College, Bronxville, New York.

Master of Science in Human Genetics and Genetic Counseling.

1981-1985 University of British Columbia, Vancouver, British Columbia.

Bachelor of Science in Biology, concentration in medical genetics.

**Specialized Training:** 

Sep 1988 California Maternal Serum Alpha-Fetoprotein Program

2002 Focus Group Facilitation and Analysis

**Professional Societies:** American College of Medical Genetics

American Society of Human Genetics Coalition of State Genetics Coordinators National Society of Genetic Counselors

**Employment:** 

Mar 1993 – present Hawaii State Genetics Coordinator

**Hawaii Department of Health** 

- Represent the health department at meetings related to genetics.
- Evaluate genetic services and programs including developing and performing needs assessments.
- Establish strategic plan for genetics program.
- Oversee fiscal resources for program (i.e. budgets, grant funding, requests for proposals and contracts).
- Write grant applications.
- Administer and implement grant activities.

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- Evaluate, plan, coordinate and present educational and training sessions to broad scope of audiences.
- Develop education materials for broad scope of audiences.
- Develop social marketing campaigns for genetics education and activities.
- Draft relevant legislation and administrative rules and regulations related to genetics.
- Monitor and testify on legislation related to genetics.
- Develop Request for Proposals and specifications for state contracts.
- Review, administer and monitor state contracts.
- Implement genetics activities in public health programs (e.g. chronic disease programs).
- Collaborate with public and private sector partners to improve genetic services.
- Develop standards and a quality assurance program for genetic services in collaboration with public and private sector programs.
- Provide input for national policies related to genetics.
- Evaluate and implement national mandates, policies, guidelines, recommendations for Hawaii.
- Recruit, retain and supervise program staff.

### Oct 1991 - Feb 1993

#### **Genetic Counselor**

# Fetal Diagnostic Center, Kapiolani Medical Center for Women and Children, Honolulu, HI

- Developed a pre-amniocentesis counseling program.
- Co-developed a Chorionic Villi Sampling program.
- Co-developed a comprehensive Triple Screening program.
- Counseled prenatal genetics patients in comprehensive prenatal diagnosis center.
- Lectured to physicians, nurses, residents, medical students, high school students and community organizations.

### Oct 1988 - Sep 1991

### **Genetic Counselor**

# Medical Genetic Services, Kapiolani Medical Center for Women and Children, Honolulu, HI

- Developed a pre-amniocentesis counseling program.
- Counseled prenatal, pediatric and adult patients in a comprehensive genetics practice.
- Lectured to physicians, nurses, residents, medical students, high school students and community organizations.

### **National Activities:**

2003 – present 2003 – present Member, Social Issues Committee, American Society of Human Genetics Member, Genetic Alliance Project CONNECT Network Empowerment Council

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# **National Activities continued**:

2002 – present	Member, Public Health Special Interest Group, National Society of Genetic Counselors
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2001 – present	Member, Industry Special Interest Group, National Society of Genetic
1000	Counselors  Provident Condition of State Condition Conditions
1999 – present	President, Coalition of State Genetics Coordinators
1999 – present	Member, Public Health Special Interest Group, American College of
	Medical Genetics
1999 – 2004	Member, Advisory Committee, National Newborn Screening and Genetic
	Resource Center
2000 - 2003	Member, Genetics Committee, Association of State and Territorial Health Officials
May 2000	Resource Speaker, Impact of Genetics on Child Health Policy Conference
,	for State Executives, Health Resources and Services Administration
1999 – 2001	Member, Diversity Project Task Force, National Society of Genetic
	Counselors
1999 – 2000	Member, Secretary's Advisory Committee on Genetic Testing Public
	Forum Steering Committee
1999	Member, National Newborn Screening Task Force, Health Resources and
	Services Administration and the American Academy of Pediatrics
Dec 1999	Resource Speaker, Impact of Genetics on Child Health Policy Conference
	for State Legislators, Health Resources and Services Administration
Nov 1999	Resource Speaker, Technical Assistance Workshop for State Planning
	Grants, Health Resources and Services Administration, Genetic Services
	Branch
1998 – 1999	Member, Ad Hoc Grant Review Committee, Health Resources and
	Services Administration, Genetic Services Branch
1997- 2002	Chair, Public Health Special Interest Group, National Society of Genetic
2002	Counselors
	Counscions

# **Regional and Local Committees:**

1998 – present	Staff, Hawaii Genetics Advisory Committee
1993 – present	Member, Hawaii Newborn Screening Advisory Committee
1993 – present	Member, Hawaii Birth Defects Program Advisory Committee
1998 - 2001	Member, Folic Acid Committee, March of Dimes, Chapter of the Pacific
1996 – 1997	Member, Hawaii Select Panel on Newborn Screening
1995 – 1999	Hawaii Representative, Region VI, National Society of Genetic
	Counselors
1993 – 2001	Member, Regional Council, Pacific Southwest Regional Genetics Network
1993 – 2001	Member, Education Committee and Access and Quality Improvement
	Committee, Pacific Southwest Regional Genetics Network
1993 – 2001	Staff, Pacific Southwest Regional Genetics Network-Hawaii Advisory
	Committee
1993 – 2001	Hawaii Coordinator, Pacific Southwest Regional Genetics Network

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# **Research Activities:**

Sep 2004 – present	Co-Investigator, Western States Genetics Services Collaborative (HRSA Grant)
Sep 2002 – present	Co-Investigator, Etiology of Hearing Loss Research Project (CDC grant)
Jun 2001 – present	Principal Investigator, Tandem Mass Spectrometry: Financial, Ethical, Legal, and Social Issues (national HRSA grant)
Jun 2001 – present	Principal Investigator, Hawaii Genetic Awareness, Implementation, and Data Project Grant (HRSA grant)
Jun 2000 – May 2002	Principal Investigator, Hawaii Genetic Assessment and Planning Project Grant, Health Resources and Services Administration, Genetic Services Branch (HRSA)

# **Conference Activities:**

1995 – present	Conference Organizer, Annual Hawaii Genetics Conference, statewide
September 2003	Education Breakout Session Organizer, "Integrating Genetic Counselors
	into Public Health and Practice", National Society of Genetic Counselors
	Annual Education Conference, Charlotte, NC
1995 - 2001	Member, Annual Conference Planning Committee, Pacific Southwest
	Regional Genetics Network, various venues in California, Hawaii and
	Nevada
2000	Member, Conference Planning Committee, 3 <sup>rd</sup> Annual National Genetics
	and Public Health Conference, Ann Arbor, Michigan
June 2000	Conference Organizer, "Genetics and Public Health: Putting the Pieces
	Together", Honolulu, HI
May 1999	Conference Organizer, "National Dialogue on Genetics for Asians and
	Pacific Islanders"
July 1998	Conference Organizer, "Genetics and Breast Cancer: Risks and Options"
July 1998	Conference Organizer, "Genetics for Primary Care Providers"
May 1998	Organizer, "Genetics Training for State Judges", "Genetics Training for
•	Lawyers", and "Genetics Training for Legislative Staff"
Sept 1997	Conference Organizer, "Genetics for Primary Care Providers"
Sept 1997	Organizer, "Genetics Town Meetings for Consumers"
Sept 1995	Conference Organizer, "Genetics and Cancer"

### **Selected presentations and publications:**

- 1. Au, SM. *Report on State by State Public Health Genetics Activities*. Coalition of State Genetics Coordinators; 1999.
- 2. Au, SM and Matsumoto, CA. Results of a Pilot Project to Determine the Cost of Active Informed Consent for Expanded Newborn Screening. Poster presented at: 2004 Newborn Screening and Genetic Testing Symposium; May 3-6, 2004; Atlanta, GA.
- 3. Au, SM, Hasegawa, LE, Fergus KA, and Ojeda, N. A Regional Project to Determine Attitudes about the Ethical, Legal, and Social Issues Surrounding Current and Future Newborn Screening for Diseases. Poster presented at: 2004 Newborn Screening and Genetic Testing Symposium; May 3-6, 2004; Atlanta, GA.
- 4. Hasegawa, LE, Au, SM, and Matsumoto, CA. The Obstetrician's Role in Newborn Metabolic Screening: A Physician Survey. Submitted for publication to Hawaii Medical Journal, 2004.
- 5. Au, SM, Hasegawa, LE and Fergus, KA. Parental Attitudes Toward Ethical and Social Issues Surrounding the Expansion of Newborn Screening using New Technologies. Submitted for publication to Pediatrics, 2004.

## Additional lectures, presentations and publications:

List available on request.